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ABSTRACT

The major contributions of research to the organization and delivery of health services in the past decade (circa 1972-1982) are described and some important areas for further research are indicated in the three main sections of this paper. The first section points out problems associated with the current state of the applied field of health services research. In the second section, contributions of health services research to maternal and child health are delineated. Research areas discussed are statistics, the structure and function of the child health care system, and advances in health and medical care (encompassing newborn, preschool, school, and adolescent periods). The present state and future of health services research are discussed in Section Three. An agenda for additional health services research is suggested and a list of 11 specific conclusions and recommendations is offered. (Author/RH)

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MATRIX NO. 4

METHODS AND SYSTEMS FOR DELIVERING MATERNAL
AND CHILD HEALTH CARE: RESEARCH CONTRIBUTIONS

by

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METHODS AND SYSTEMS FOR DELIVERING MATERNAL AND CHILD HEALTH CARE: RESEARCH CONTRIBUTIONS

Other speakers have outlined the major illnesses of children today and what biomedical research has achieved in the past 10 years to reduce the burden of these illnesses on children. The end result should be the translation of these biomedical findings, through the organization of the health care system to deliver services of proven effectiveness to all children in the nation. My challenge is to outline some of the major contributions of research on the organization and delivery of health services in the past decade, and to outline some of the important areas for further research. In this short summary I will not document statements, but have listed a short general bibliography as backup.

I. What is Health Services Research?

Health services research is concerned with understanding the planning, organization, staffing, financing, management, operation, maintenance and use of health services delivery system. It also includes evaluation and analysis of the system's efficiency, effectiveness and efficacy (Flook *et al.*, 1973).

Table I lists the main areas with which health services research is concerned. Since there is not a separate discipline of health services researchers, but rather a collection of workers drawn from many disciplines, frequently with each group specializing in only one or two of the areas listed in Table I, there has been a tendency for fragmented research findings. One group will report on economics without considering the impact on quality and vice versa. Since health services research is a *seamless interconnection* of people to providers and institutions, there is a need in the future for more research that spans the various areas listed in Table I and addresses their interrelatedness and the impact of change in one area upon all other areas. This is quite opposite from the usual approach to research, which is to narrow and focus on as few variables as possible, and to isolate these variables from other contaminating forces. But health services research is an applied field, whose major (perhaps, only) justification is to improve health through improving the organization of health services in the real world. There has been too little integrative type of research in health services and too little cumulative or building upon the work of previous workers.

Health services research has been hampered by a lack of reliable and valid methods, especially to measure the outcome in functional terms of most causes of disease. One problem is that there is no global way to define function. A child may function well intellectually but poorly in locomotion or vice versa. A few workers in the child health field have begun to develop ways to *profile* a patient's health and to develop reliable methods to measure function in several dimensions and the impact on the child and family of illness. Until further development of methods occurs, however, which can be used by many workers, the cumulative type of approach that I have urged will be difficult. The situation is analogous to traditional medicine a generation ago. Until a reliable blood sugar method was available, the study of diabetes mellitus was limited.

TABLE I
SOME SELECTED AREAS OF HEALTH SERVICES RESEARCH

FACILITIES

Bed needs, distribution, health centers, hospital design

MANPOWER

Supply, type, distribution, tasks, education

ORGANIZATION AND ADMINISTRATIVE

Group practice, international comparisons
Regionalization

ECONOMICS

Costs, control, financing, public programs (medical), insurance

UTILIZATION

Hospital, ambulatory, emergency rooms,
Focus on the poor

EVALUATION - QUALITY

Efficacy, effectiveness, efficiency
Methods of measuring outcome, statistics
Technology assessment

SOCIAL BEHAVIOR

Why people use health services, compliance
Patient-provider communication
Social determinants of health

In most social sciences, development of new methods has not been given high priority. While pure methods research is unlikely to attract the best researchers, development of new methods should be supported as part of other health services research projects. A search for proxies of complex behaviors and function should have high priority. It never will be possible to examine large numbers of individuals to ascertain function and, therefore, simple, and yet reliable and valid, proxy methods need to be developed. We also need better measures of the input or independent variable in order to know what are the ingredients of a successful program in order that it can be replicated.

II. Contributions of Health Services Research to Maternal and Child Health

A. Statistics:

One of the major contributions that research has made in the past decade has been to define more clearly the true prevalence of health problems in the population and to help direct resources toward areas of greatest need. For instance, it was barely a decade ago that the Sudden Infant Death Syndrome was defined clearly and taken out of the statistical grouping *accidental*. With this statistical clarification, and a good deal of advocacy, researchers now have built a much clearer case about the causes, and even possible interventions, for this major cause of death after the newborn period. Likewise, the clearer definition of the burden placed upon children and families by such common problems as respiratory infections, chronic physical diseases, school learning disabilities, substance abuse and the recent increase in mortality from homicide and suicide in adolescents, all have helped to define new targets for the health system to address. Refined statistics such as these may not strictly be health services research, but they form the *intelligence* upon which any rational system of health care must be built. The United States now has a very good national system of health data through the National Center for Health Statistics Reports and Surveys. These, however, are limited to death and common causes of morbidity. We still lack local community data to indicate differences in need, and we especially lack measures of function and impact of illnesses. In only a very few communities have repeated measures of child health been developed, such as in Flint, Michigan and Rochester, New York. These studies are particularly important because they document the changes in utilization of services and level of health in the community over a period of several years. They are cross-sectional, however, and do not detail what happens to individual children. There are only a very few longitudinal studies of the same children, and most of these in the United States have some special focus — that is, respiratory infections, behavioral problems, substance abuse, etc. Since longitudinal research is so expensive, the numbers of children followed longitudinally have been small in all of the studies. However, this should not diminish the importance of longitudinal studies for, as Brunswick has shown, there is considerable variation as to which children are sick at different ages. This lack of stability of health and illness in individuals (if it can be demonstrated in other settings) is of special importance to the organization of health services, for it means that we cannot have too targeted a health care delivery system if one cannot easily pinpoint permanent high risk groups. Coordinated longitudinal studies of health and use of health services by the same children are high priority needs.

Some relatively simple additions to our statistical system would improve our intelligence and make evaluations easier. Linkage of birth and death certificates, adoption of the uniform ambulatory and hospital data set, use of some identifying number for patients, and social class determinations in birth and death certificates are examples of such needed additions to our statistical system.

Continued support of our present excellent statistical system with some of these additions especially will be important in the years ahead as we undertake a national experiment with block grants. We will be able to learn a great deal from this experiment and the many state variations, if we monitor results carefully with an expanded statistical system.

B. Structure and Function of Child Health Care System, 1980

Research in the past decade has identified quite clearly the distribution of health services in the United States for children. In broad strokes, the majority of children receive their health care within the private sector (some 75% to 80%). During the past decade, there has been considerable increase in the percentage of poor children who are cared for through public programs (Medicaid, children and youth programs, maternal and infant care programs, and comprehensive neighborhood health centers). As a result, the social class differences between the amount of medical care received by the poor, and the less poor, have now diminished. There remains some 10% of children (most heavily concentrated in the poverty group) who do not have a medical home and who receive inadequate care, although not a total absence of care. It also has been made abundantly clear, from research in the past decade, that social class remains a major proxy and, in some way, is related to a number of health problems and the way in which medical care is received. Lower social class children face a larger burden of illness of almost all kinds while, at the same time, are more apt to receive fragmented care. While the nation has gone a long way to see to it that poor children are treated equally, their needs are greater and, therefore, mere equality may not be satisfactory. There is need to continue to press for expanded health services for poor children, and to focus research on ways to reduce perceived barriers by the poor of the health care system and to understand the underlying causes of the greater burden of illness upon poor children.

C. Advances in Health and Medical Care

Major advances in the health of children have been achieved through biomedical research and the application of this research to large numbers of children during the 1970s. It is difficult to separate the contributions of biomedical research from those regarding the organization and delivery of health care. In general, the application of technology has occurred with great speed, often before evaluation of the usefulness of the technology could be accomplished (e.g., CAT scan). In other instances, there has been a delay in the delivery of known efficacious biomedical advances (e.g., measles vaccine and poliomyelitis vaccine required more than a decade, and continued special efforts, to achieve nearly universal immunization in preschool children). Some examples of successful applications follow:

1. Newborn Period

In the newborn period, there have been advances in the knowledge of diseases peculiar to the newborn (hyaline membrane disease, especially).

Improvements in neonatal intensive care and regionalization of perinatal care have been accompanied by, and probably in large part the cause of, a remarkably lower death rate in the newborn and in the first year of life. This has been achieved without seriously increasing the number of handicaps in the survivors (although there is still a debate about this last statement). The dramatic decrease in infant mortality throughout most of the United States in the past decade raises the question of whether this is caused entirely by the biologic knowledge and treatment of disease, or whether there is also a contribution from improved nutrition of mothers throughout the W.I.C. program, as well as job programs and some general improvement in the environment (decreased lead, air pollution, etc.) Careful evaluation of the effectiveness of regionalization of newborn care is being carried out by Shapiro at Johns Hopkins. Such evaluations of large-scale programs need to be continued.

Behavioral research in the newborn and infancy area has demonstrated the importance of early bonding of mother and child and the effectiveness of early stimulation, especially of language for children with inadequate stimulation at home. Rapid changes in the organization of newborn services have resulted in most newborn services now making major efforts to deliver mothers without sedation, in order to promote infant-mother contact in the first few hours of life. At times this emphasis may have gone too far, since there is some evidence that a good deal of maternal guilt is being generated when early bonding cannot occur. Infant stimulation and support systems, through home nurse visiting, has been applied to the high-risk population with quite good evidence for improved outcome of pregnancy, as well as improved development of children and reduced risk from such problems as child abuse. The research evidence available here, as in so many areas, is largely from small-scale studies done by enthusiastic leaders of the field. The next level of research should attempt to expand these services to larger groups of high-risk populations in an effort to determine whether the results can be replicated when built into a general system of care. One of the ways to overcome the lack of generalizability from small-scale studies is to organize collaborative groups, all using similar core research methods, in different areas of the country. Coordination of collaborative studies should be a major function for federal and private foundation supporters of health services research.

2. Preschool Period

During the preschool period of childhood, improved immunizations and their delivery to a larger percentage of children have resulted in dramatic decreases in communicable diseases. Poison information centers, safety caps on medicine bottles and the diminished use of aspirin (acetaminophen has been substituted) all have resulted in the reduction of mortality from accidental poisonings, even though the total number of ingestions seems to have remained roughly the same. Dramatic breakthroughs have occurred in the

treatment of patients with leukemia, with now well over half of the number of children with acute leukemia surviving more than 5 years. Regionalized cancer centers have brought this care to most children in the country. Automobile accidents have not been as successfully dealt with, however. Indeed, the major success in auto safety has come as a byproduct of the reduction of the speed limit and the mandatory seat belt and infant car seat requirement in a few states. Educational efforts to encourage parents to use restraining car seats for infants and children have not met with high compliance.

Generally, the physical health of preschool children has improved dramatically, and mortality and morbidity are at low levels at this period. Three major needs of research in this age group are: to address the continued problems of accidental deaths and morbidity; to determine the effectiveness of various screening tests (their timing, content and methods of follow-up); and to place greater emphasis upon the behavioral problems of this age group, their course, relation to future health problems and the effectiveness of intervention for them.

3. School and Adolescent Period

During the school and adolescent years, there has been much less progress. Indeed, in late adolescence, death rates have even increased in the past decade. Some of the past advances in the care of children with leukemia and cancer have been overshadowed by the greater risk of children dying of suicide, homicide and accidents. These problems, together with the behavioral consequences of teenage pregnancy, substance abuse, psychological consequences of chronic physical disease and school learning problems, all have made adolescent health appear to be the major challenge to child health in the next decade.

There appears to have been very little services research addressing these problems. The field has been characterized by either neglect, or by high, but uncritical, enthusiasm by those involved. Careful evaluation of new programs, for all of the problems listed above, is necessary. They are difficult to achieve because, in many instances, the problems, although serious and relatively common, occur with such low frequency (e.g., suicide) that very large population studies are necessary to be able to evaluate the effectiveness of intervention programs.

III. The Present and Future of Health Services Research

In spite of dramatic advances in the biomedical knowledge and the application of this knowledge to selected populations, there has been, by comparison, a dearth of research in health services. The high promise that the creation of the National Center for Health Services Research and Development brought forth, slightly over a decade ago, has not been realized, in large part, because of the very anemic funding of this agency and, in part, because relatively little of its meager resources have been concentrated on training skilled researchers in this field. The small sums available, through the Maternal and Child Health Ad-

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ministration, have helped considerably in the understanding of how child health services work, as well as in supporting a modest amount of research, but the efforts have been too small for the challenge. There has been very little support of research in health services from the National Institute of Child Health and Human Development.

We have learned from research, during the past decade, that continuity of care can do many things promised by its supporters; namely, increase compliance with medical regimens, decrease broken appointments, decrease hospitalization, and decrease the cost of laboratory and drug use. Such studies are especially important in today's cost-conscious era. On a small scale at least, costs can be constrained by appropriate organization of health services without diminishing and, indeed, usually improving the quality of care. A great deal more research into methods of cost containment needs to be carried out, while, at the same time, assuring the quality of care. Unfortunately, these issues, like so many others in health services research, are tied closely to the political forces at the time. It would be reassuring to believe that more and better data on the effectiveness of different ways of organizing health services would lead to the implementation of the findings. The failure of this match to occur in the past suggests that a major area for health services research in the future is to study, and to better understand, how the political system can be influenced, and how health services research can be translated into effective programs. Health services research differs from many other areas of research in that its only reason for existence is to apply the fruits of other research. Unless it considers the political and economic consensus necessary for implementation, it will accomplish very little. It cannot focus only on merit or efficacy.

Health services research has demonstrated the great gap that exists in many communities between the promise of health care for all, and the reality of it for some. It also has demonstrated the most important social, educational and environmental causes of ill health in children while, at the same time, demonstrating the lack of integration of human services that are necessary to tackle these boundary problems. Education, social environment, and health, all intimately are bound together. There are dangers in health services research taking on the entire field of human endeavor, and yet, it is clear that the impact of social class, stress, environment and education is so important to children's health that some effort needs to be made to integrate them effectively and to evaluate these programs.

My own interest in the behavioral issues of child health may strike some as overemphasis. I do not want to dismiss the important gains in care of physical diseases, and the need for research at the biological level. It is important to recognize, however, that successful treatments applied to the remaining physical illnesses (congenital anomalies, inborn errors of metabolism, etc.) will reduce mortality only a small amount because they are all quite rare. In contrast, the behavioral aspects of many chronic physical diseases (both as the cause of some and the consequences of others) and the very large burden of psychological problems themselves upon children require special attention from

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researchers in the next decade. Purely behavioral problems cause distress and dysfunction in some 10% to 20% of children. To date, only 20% to 30% of children of these are identified and are under care in our current health care system. We certainly need more studies on the long-term consequences of behavioral problems, but some evidence now is available that young men with behavior disturbances are more likely to have a variety of chronic physical diseases over their lifetime. Social stress, especially if not associated with a social support system, can lead to higher death rates and more chronic physical diseases. A very high priority should be placed on studies of how to deal with behavioral disturbances in children.

Targeted versus comprehensive services is a major issue among organizers of health care and researchers. There are good arguments for both approaches. Comprehensive services are justified by the need of all children for certain services, the difficulty parents have in selecting a specialty service, and the lack of stability of high-risk groups (which means that children now considered low-risk, and not the focus of a targeted approach, may move into an at-risk group, but miss a needed service). Targeted services, on the other hand, conserve resources, focus providers', as well as patients', attention; often result in more completeness of a service; and are easier to evaluate. The issue is not whether targeted or comprehensive; but rather under what circumstances is one method better, and under what circumstances is the other better. Research on these two major approaches to the organization of health services should have high priority in the decade ahead.

Another major issue is: Who is to provide health services for children, especially newer services such as nutrition or psychological services? Research on efficacy and cost of alternatives should receive support.

The recent report of the Select Panel on Child Health outlined a very important series of recommendations. The research bases for these recommendations were well-documented, but it is evident that the health services research base, to prove the effectiveness of many of their recommendations, is not available.

As a modest agenda for additional health services research, I would include the following:

1. Study of effective ways to teach children, especially young adolescents, to develop healthy lifestyles in order to reduce the incidence of adult chronic disease.
2. Studies of the mechanism by which social class is such a pervasive cause of ill health and problems in the utilization of health services. Intervention studies should then be carried out to determine how to overcome these mechanisms.
3. Studies of how to intervene effectively to help children and families with psychosocial dysfunctions. The range of problems that seem to be highly associated with family dysfunction, from child abuse to mental retardation, from lack of stimulation through to learning problems, and adolescent behavior disturbances, suicide, homicide, accidents, teenage pregnancy, and

substance abuse, make focus on the dysfunctional family a high priority item. The psychological consequences of chronic physical disease are especially crucial to health-services research needs.

To achieve even a modest number of these goals will require the training of skilled health services researchers who are now in short supply. Perhaps the first step should be a program to train a variety of disciplines in health services research. The National Center for Health Services Research has made a modest beginning with the support of doctoral dissertations. However, pre- and post-doctoral programs and, even more important, the support of the research portion of the early career of such trainees, should receive high priority from both the private and public sector, if we are to address the health care needs of children in the future.

Conclusions and Recommendations

1. Health services research should place greater emphasis upon cumulative studies that build on past advances and do more *total system* studies, rather than isolated and focused studies.
2. There should be further emphasis upon development of methods to measure more precisely the outcome of health care by the use of profiles and measures of function and impact upon the family, as well as the input or independent variable.
3. The excellent existing data from the National Center for Health Statistics should be supplemented with selected community-wide studies repeated every few years, as well as a few longitudinal studies of individual children and their changing need for health services. The lack of stability in children at high risk suggests that our child health system must avoid an overly-targeted approach. Implementation of linked birth and death certificates, and adaptation of the uniform ambulatory and hospital discharge abstract would help to monitor changes in health services.
4. Programs of financing and organizing medical care for the poor, organized in the 1960s and 1970s, nearly have equalized the use of health services by the poor, as compared to other children, but health needs remain greater among lower social class. Continued efforts must be made to expand the services for the poor, and address research to the underlying causes of greater illness among poor children.
5. Regionalization of newborn care, bonding, home nurse visiting, and infant stimulation programs have shown efficacy in small settings. The next challenge to research is to translate these to larger scale projects and measure their effectiveness. Before widespread application of any new technology, there should be careful evaluation of its effectiveness.
6. After the newborn period, in both the preschool and school age group, the greatest needs today are to study how to reduce the burden of accidents, to determine the most effective and efficient methods and timing of screening tests, to study the long-term effects of behavior problems, and to study how to intervene effectively.

7. Health services research has made major contributions to our understanding of what works and what doesn't. Implementation, however, has been limited by political considerations, thereby suggesting greater emphasis should be placed on research to understand how to implement the results of the research.
8. Integration of social, educational and health problems and research to evaluate such integration across strong disciplinary barriers need emphasis.
9. High priority should be given to studies of how to help adolescents develop healthy lifestyles and how to intervene more effectively in family dysfunction problems.
10. A major question among organizers of health services is: When are targeted services best, and when are general or comprehensive ones crucial? Research on this issue will be essential over the next decade.
11. Strong efforts should be made to train a cadre of skilled investigators and to provide research support during their early careers. Lack of such researchers may be the most important problem to overcome before we successfully can address the research agenda I have outlined.

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